

# Supporting family carers in end of life care

GE Grande  
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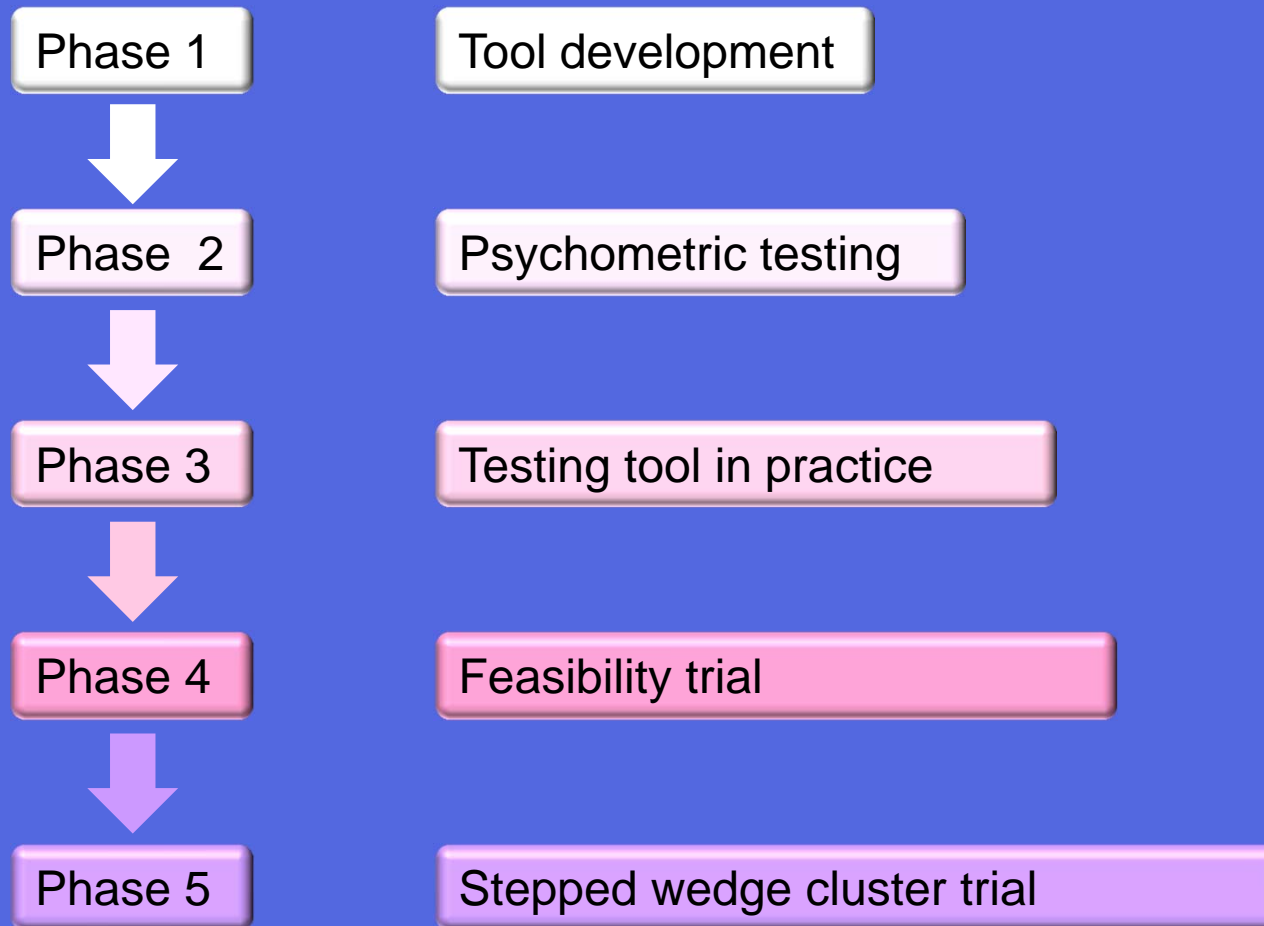
University of Manchester  
University of Cambridge

# Background

- Most people prefer to be cared for at home towards the end of life<sup>1</sup>
- Family carers are essential in supporting end of life care at home
- Carers need to be supported to reduce adverse effects



# Overview of carer support needs assessment work



# Designing a Support Needs Assessment Tool (CSNAT)

Phase 1

## Sample

- 75 bereaved carers
- 5 H@H services across England
- cancer / other progressive illnesses

## Data collection

- 9 Focus Groups
- 22 telephone interviews

## FG / interview content

- key aspects of support in last 2-3 months
- what are the main domains
- what input was supportive?

Audio recordings fully transcribed  
Thematic analysis



# Dual role of carers: providers of care

Key areas: support with ....

- knowing who to contact when concerned
- equipment to help with caring
- managing symptoms and medicines
- providing personal care
- understanding their relative's illness
- knowing what to expect in the future
- talking to their relative about their illness



# Dual role of carers: recipients of care

Key areas: support with ....

- day time respite
- own physical health concerns
- practical help in the home
- financial and work issues
- dealing with their own feelings and worries
- beliefs or spiritual concerns
- overnight break from caring



# CSNAT design for psychometric testing

### Your support needs now

We would like to know what help you need to enable you to care for your relative or friend and what support you need for yourself. Please tick the box that best represents your needs now, for each statement below.

Do you need more support with...	No	A little more	Quite a bit more	Very much more
... understanding your relative's illness				
... having time for yourself in the day				
... managing your relative's symptoms, including giving medicines				
... your financial, legal or work issues				
... providing personal care for your relative (eg dressing, washing, toileting)				
... dealing with your feelings and worries				
... knowing who to contact if you are concerned about your relative (for a range of needs including at night)				

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### continued)

We would like to know what help you need to enable you to care for your relative or friend and what support you need for yourself. Please tick the box that best represents your needs now, for each statement below.

Do you need more support with...	No	A little more	Quite a bit more	Very much more
.. looking after your own health (physical problems)				
.. equipment to help care for your relative				
.. your beliefs or spiritual concerns				
.. talking with your relative about his or her illness				
.. practical help in the home				
.. knowing what to expect in the future when caring for your relative				
.. getting a break from caring overnight				
.. anything else (please write in)				

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Input on design:

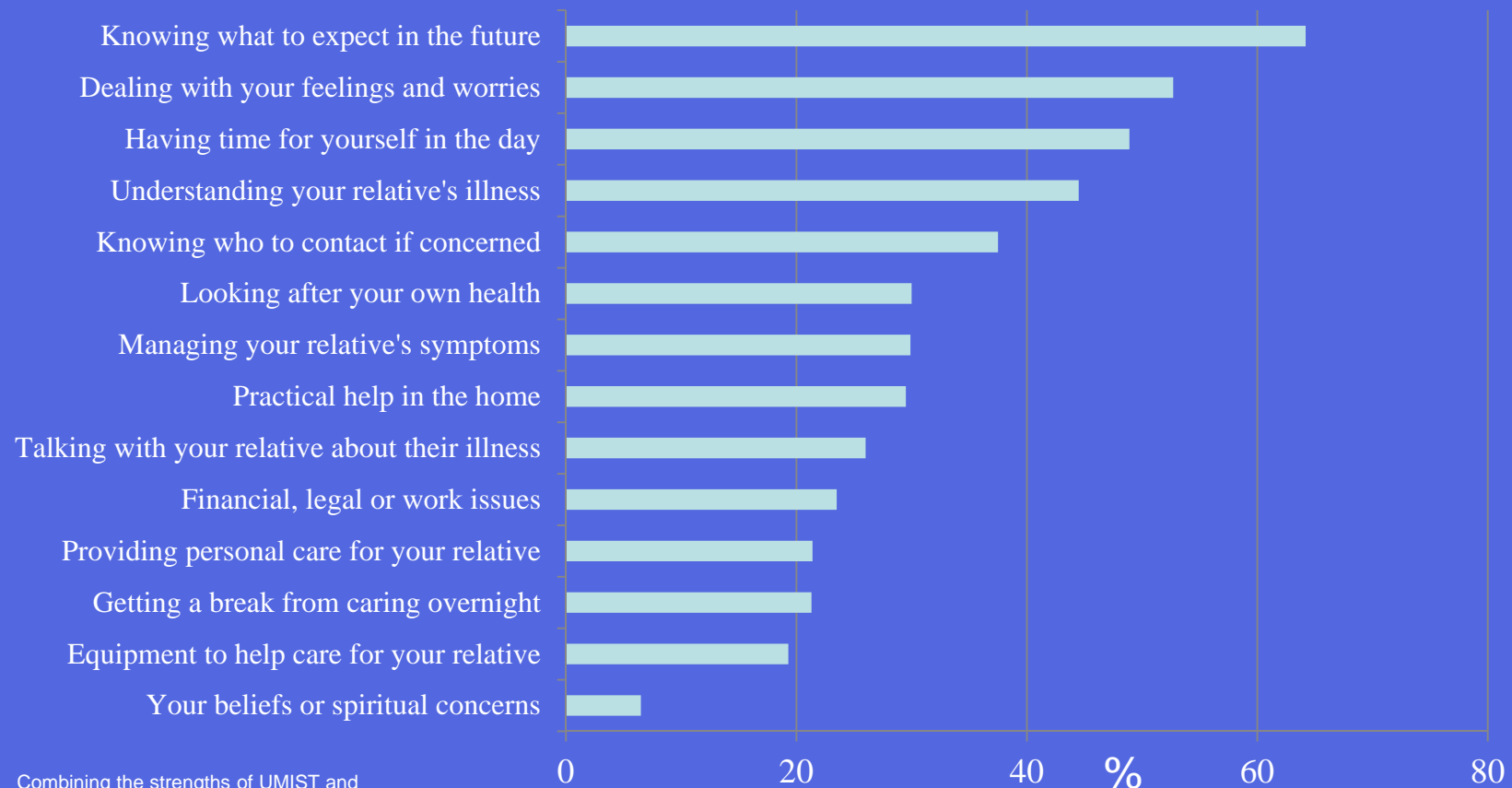
Carer advisory group

National Forum for Hospice at Home Research Advisory Group

# Psychometric testing of the CSNAT

Survey of 225 current carers, 6 HHC Services

Content validity: all items used, no items missing



# Psychometric testing of CSNAT

Criterion validity:

Greater need for support was significantly related to

- Lower preparedness for caregiver role
- Higher care giver strain and distress
- Worse quality of life
- Need for support with personal care, equipment, respite and practical help in the home significantly related to patient's problems with ADL

# The CSNAT tested as practice intervention

One HHC Service: Service components

Training issues; plan for implementation ; monitoring and review

Which carer details?

**COLOUR!**

Prioritisation of support needs

St. Luke's Homecare @ Home  
 spd@s nursecare CIC

**Carer Support Needs Assessment Tool**

Today's date: .....

Name of carer: .....

Name of cared for person .....

The person I care for is my .....

How was this form completed? (Please tick one)

By carer alone

By carer and St Luke's nurse together at home visit

By carer and St Luke's nurse together by telephone

Any other way, (please explain below)

Combining the strengths of UMIST and The Victoria University of Manchester

**Your support needs now**

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Do you need more support with...	No	A little more	Quite a bit more	Very much more
.. understanding your relative's illness		<input checked="" type="checkbox"/>		
.. having time for yourself in the day		<input checked="" type="checkbox"/>		
.. managing your relative's symptoms, including giving medicines			<input checked="" type="checkbox"/>	
.. your financial, legal or work issues	<input checked="" type="checkbox"/>			
.. providing personal care for your relative (eg dressing, washing, toileting)	<input checked="" type="checkbox"/>			
.. dealing with your feelings and worries	<input checked="" type="checkbox"/>			
.. knowing who to contact if you are concerned about your relative (for a range of needs including at night)	<input checked="" type="checkbox"/>			

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**(continued)**

We would like to know what help you need to enable you to care for your relative or friend and what support you need for yourself! Please tick the box that best represents your needs now, for each statement below.

Do you need more support with...	No	A little more	Quite a bit more	Very much more
.. looking after your own health (physical problems)	<input checked="" type="checkbox"/>			
.. equipment to help care for your relative		<input checked="" type="checkbox"/>		
.. your beliefs or spiritual concerns	<input checked="" type="checkbox"/>			
.. talking with your relative about his or her illness	<input checked="" type="checkbox"/>			
.. practical help in the home	<input checked="" type="checkbox"/>			
.. knowing what to expect in the future when caring for your relative		<input checked="" type="checkbox"/>		
.. getting a break from caring overnight	<input checked="" type="checkbox"/>			
.. anything else (please write in)	<input checked="" type="checkbox"/>			

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Method of completion?

On previous pages, please circle support needs prioritised.

Reviewed	Done completed

Signed .....

H@gH co-ordinator / H@gH service carer (delete as appropriate)

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 For permission to use the CSNAT tool, contact Dr Gail Ewing, Centre for Family Research, University of Cambridge, Free School Lane, Cambridge CB2 3RQ (g.e209@cam.ac.uk)

Actions taken

Research components:

use in practice, understanding CSNAT as an intervention

### Focus group: use of the CSNAT

*“I think everything on there is what I would have expected, because I think that’s more or less the areas that we were covering anyway in one way or another isn’t it? (R1)*

*It is, but the one talking about your relative, about his and her illness and knowing what to expect in the future are things that we don’t ask routinely”. (R2)*

### Audio diaries:

*“What I found particularly useful [with CSNAT] was the things I thought she [carer] might not be able to cope with, were the things she was coping with. And the things she wasn’t able to cope with, I was quite surprised.” (R5)*

*“The CSNAT was really useful on this occasion because the wife burst into tears and said ‘no one has really asked me about what I wanted’.” (R3)*

# Feasibility trial of CSNAT

Before-after study in one hospice home care (HHC) service

Implementation and data collection run separately

Implementation of CSNAT with all carers after a five month 'before' period

Recording of process

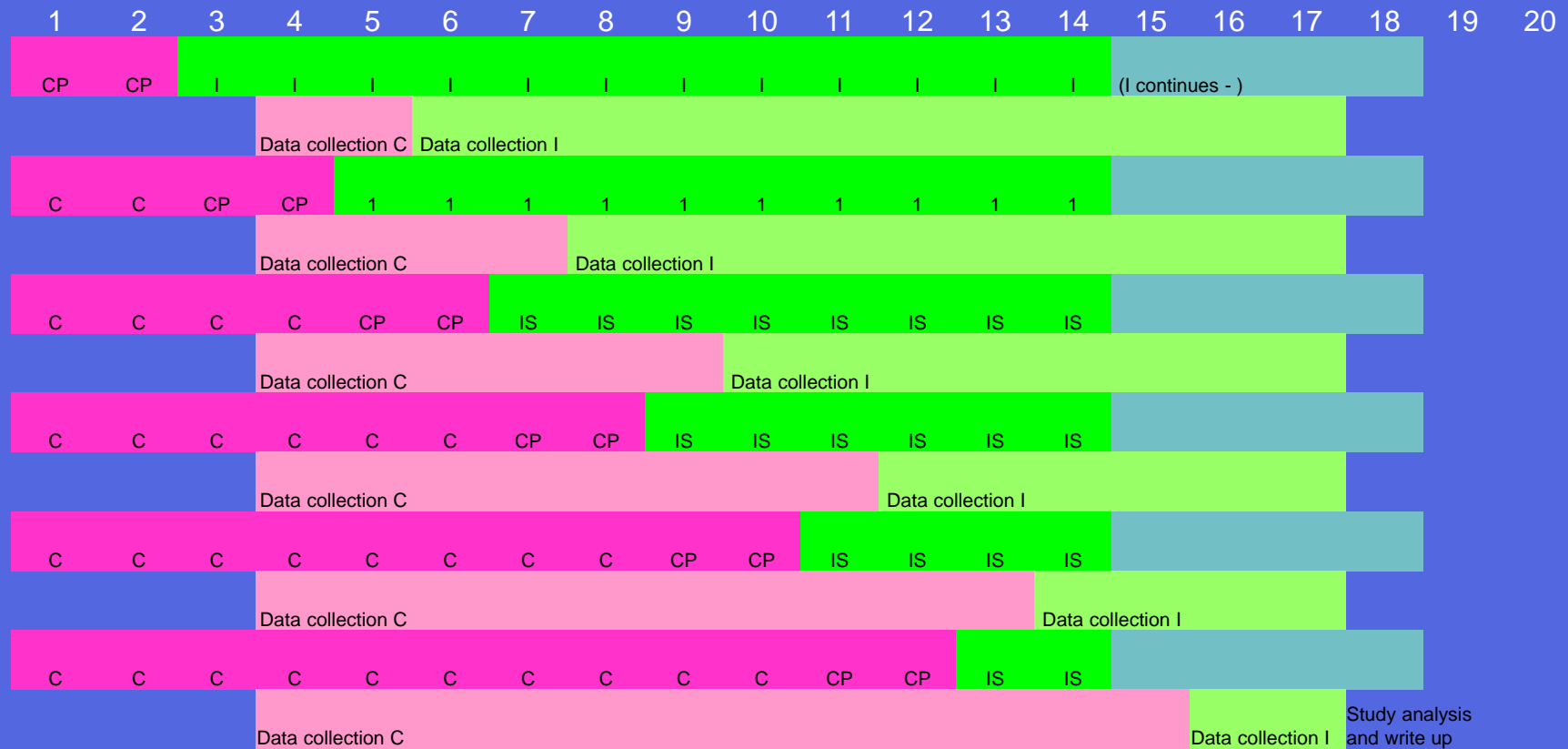
Outcomes data collection: survey 3-4 month post bereavement, including mental/physical health, needs

**Aim:** 95 carers in each condition

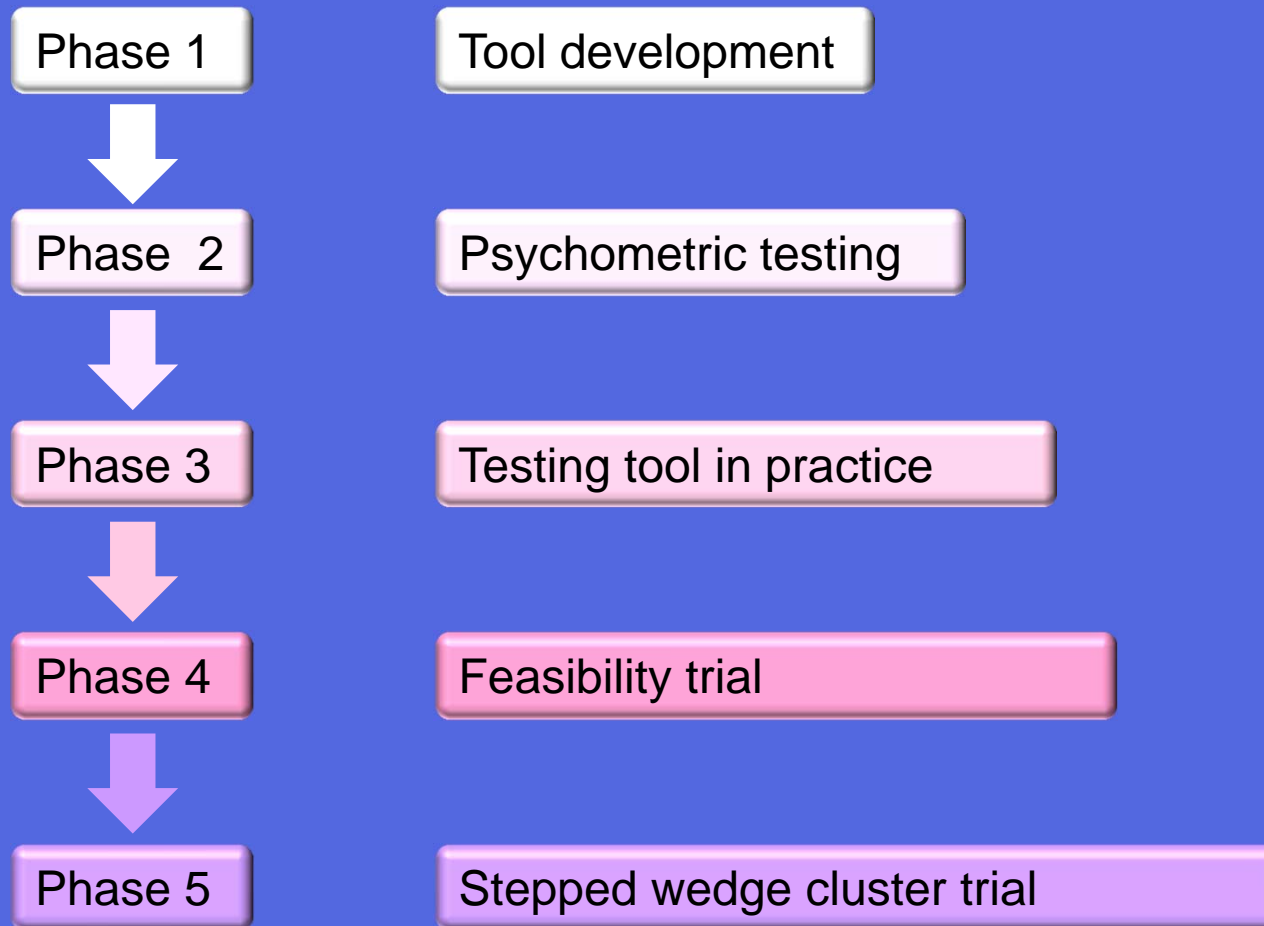
# Feasibility Trial outline

Month	-3	-2	-1	1	2	3	4	5	6	7	8	9	10	11-15
<b>Intervention</b>	<b>Standard care (Before)</b>					<b>CSNAT intervention (After)</b>					<b>(Service continues to use CSNAT in practice)</b>			
<b>Data collection</b>				<b>3-4 month post-bereavement survey- (Before)</b>					<b>3-4 month post-bereavement survey – (After)</b>					<b>Analysis &amp; report</b>

# Stepped wedge cluster trial



# Overview of carer support needs assessment work



# Future developments

Feasibility study of implementing CSNAT in primary care



Cluster RCT  
CSNAT in  
primary care

Qualitative  
case study

Qualitative  
case study

Longitudinal  
study  
CSNAT as a  
carer held tool

Wider HHC  
implementation  
Facilitating and  
obstructing  
factors

# We wish to thank the following

- National Forum for Hospice at Home
- Burdett Trust for Nursing
- Dimbleby Cancer Care
- BUPA Foundation
- All the hospice home care staff and family carers who have helped with the project

## REFERENCE

- Department of Health (2008). End of Life Care Strategy: promoting high quality care for all adults at the end of life.



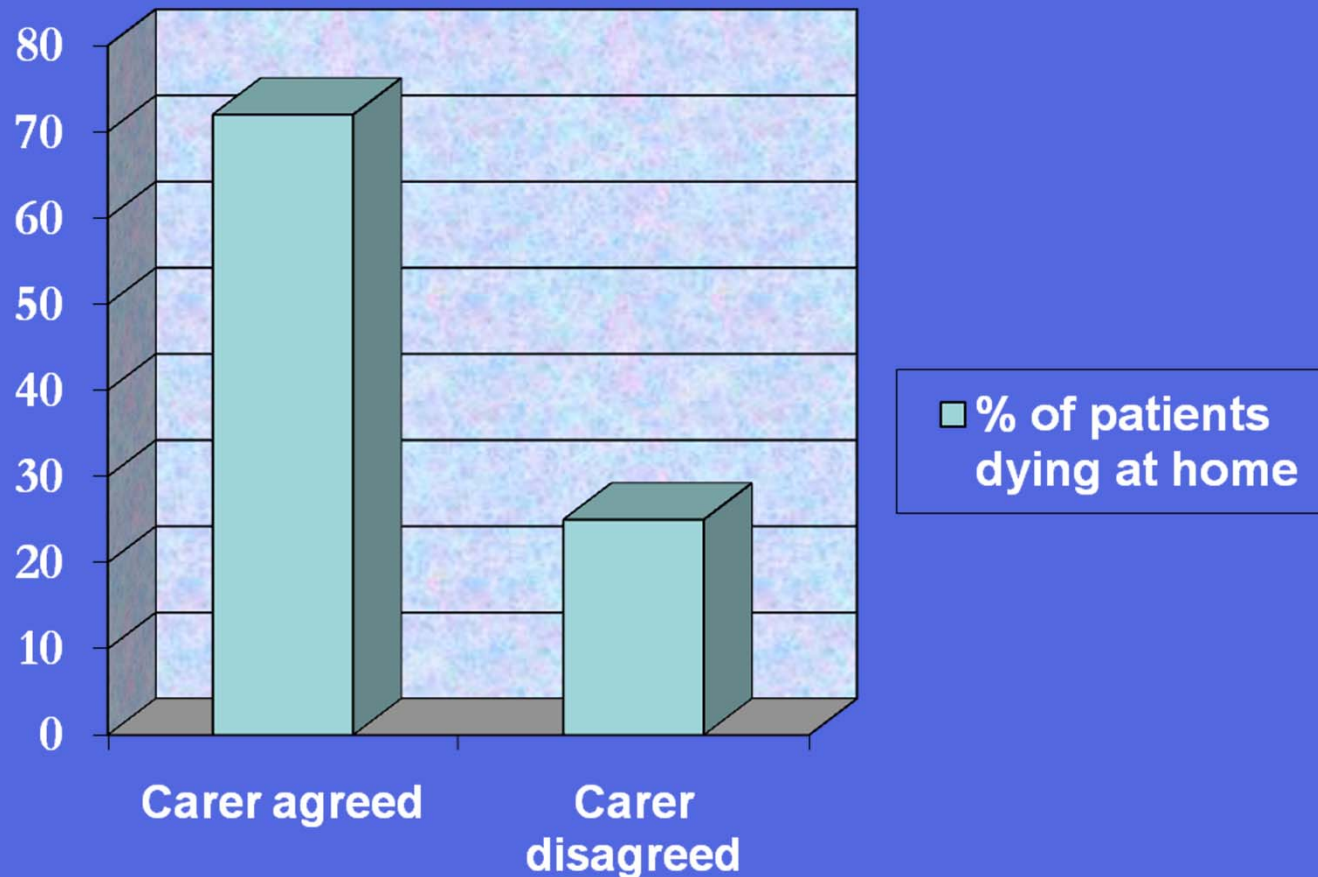
Level of grief in bereavement lower if the carer had sufficient psychological support and information in the patient's last two weeks of life<sup>1</sup>



# Likelihood of dying at home

79% of patients wanted to die at home<sup>1</sup>

NFFH@H  
STUDY



<sup>1</sup> Grande & Ewing (2008)

# Mental health in bereavement relates to level of psychological support and information in the patient's last two weeks of life<sup>1</sup>

